DOCUMENT RESUME

ED 260 551 EC 180 518

AUTHOR Provencal, Gerald
TITLE Confessions of a Community Placement Optimist.
PUB DATE Nov 84
NOTE 11p.; Paper based on presentation at the Annual Conference of the Association for Persons with Severe Handicaps (11th, Chicago, IL, November 8-10, 1984).
PUB TYPE Viewpoints (120) -- Speeches/Conference Papers (150)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Community Programs; *Developmental Disabilities; Normalization (Handicapped); Personal Narratives; *Placement; Social Attitudes; Staff Role

ABSTRACT

This paper offers reflections from the author's experience with community placement for developmentally disabled persons, specifically addressing practical and philosophical issues. Drawn from the author's personal involvement with the Macomb-Oakland Regional Center (MORE) in Michigan, this document notes nine illustrations of progress from 1969-1984. It is suggested that staff at MORE are helped to acquire a sense of urgency, a sense of ownership for solving the problem, commitment to action on behalf of the consumer. Among different ways that agencies and associations have battled successfully with their own service structures are factors involving: relationships with parents, readiness reversal (suggesting that virtually everyone can move into the community if the right alternatives are created), staff specialized in developing homes, approaches to dealing with the news media, and decisions to avoid distractions that could lead workers off task. Threats to momentum, including prejudice, complacency, and the pull of "institutional gravity," are considered. The paper concludes by asserting the importance of seeing the larger picture in the lives of developmentally disabled persons. (CL)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED260551

U.S. DEPARTMENT OF EDUCATION
NATIONAL INSTITUTE OF EDUCATION
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
This document has been reproduced as received from the person or organization originating it.
Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official NIE position or policy.

"CONFESSIONS OF A COMMUNITY PLACEMENT OPTIMIST"

Gerald Provencal

BEST COPY AVAILABLE

EC 180518

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
Gerald Provencal
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

I. INTRODUCTION

Replacing institutions for developmentally disabled citizens with normative homes in the larger community remains an evocative subject. Everywhere you travel, parents, professionals and the tangled knots of agency systems are engaged in some phase of community placement; in its generation, defense or denigration. It is my observation that those who spend time in the latter pursuit seem to become leaner and meaner as their arguments are gelded with immutable facts. Uncertainties about community placement, its moorings and the construction which keeps it afloat, are not, however, the exclusive property of the critics. Each of us with a connection to the developmentally disabled population, no matter which side of the debate has caught us up, must still feel less than satisfied with some part of the concept's translation into a program we are familiar with. The balance between the successes we know of and our private dissatisfactions determines, I suppose, whether we view placement as holding dramatic promise for all our consumers or only those in select strata with lighter developmental needs.

In the space permitted this paper, I would like to offer personal reflections from my experience with community placement for developmentally disabled persons (which I view as holding dramatic promise). I would specifically like to touch on practical and philosophical issues which can lead to the concept maintaining a robust state of health.

My frame of reference has largely been defined by work that has gone on within the State of Michigan and more particularly at the Macomb-Oakland Regional Center. Although the lessons were drawn from one region of the country, I am convinced that in spite of provincial differences the fundamental plight of persons with developmental disabilities remains the same and the answers change little when borders are crossed.

II. MICHIGAN PROGRESS 1969-1984

A review of the gains made in Michigan by people with developmental disabilities shows a radical change in life styles over the past 15 years.

- In 1969 there were approximately 12,000 people with developmental disabilities living in the state's institutions. By the end of 1984 there will be just over 2,100.

- In 1972 Michigan had 12 institutions for persons with DD, two new institutions were on the verge of construction and there were tenative plans for the building of at least two more. By 1984, the State not only had dropped plans for erecting the second pair but had closed four additional institutions. The most recent to close (Plymouth Center for Human Development) was considered a model when it opened its bright wards in 1962.

- In the early 1970's, the State had entered into contracts with several nursing homes to operate residential programs for approximately 1,000 mentally retarded persons with "basic" or "skilled" nursing care needs. By 1984 three of these nursing home programs had been closed with the likelihood that the State will eliminate participation in the program entirely.

- As late as 1974 in the Macomb-Oakland region, with its 2 million population, there was only a handful of small group homes (4-6 residents) and those that did exist were for the least handicapped. Ten years later there are 134 such group homes for people with developmental disabilities, and they have proven versatile enough to be considered the home of choice for even the most complexly handicapped consumers.

- In the early 1970's, within the Macomb-Oakland catchment area, there was only a modest complement of foster homes for persons with developmental disabilities. The homes that did exist were almost exclusively for children, and those with the most limited problems at that.

- Today there are over 200 families in this region who, because of specialized recruitment, training, support and financial subsidy provide homes for over 250 children and adults. These 250 represent all manner of secondary handicaps which compound their developmental disability.

- Less than a decade ago within the same region there were no specialized apartments, no parent trainers, no cash subsidies to natural families, no respite homes, and no zoning law that permitted ready access to single family neighborhoods for small group homes. Today each of these features is in place and growing in number of influence.

- In the five year period prior to Macomb-Oakland's creation in 1972 a yearly average of forty area developmentally disabled citizens were sent to the State institutions' dormitories as "new admissions." There has not been a new admission to such an institution for over six years. The people who formerly would have moved to some state school campus now move into community based homes.

- Ten to 15 years ago the parents of newborn children with developmental disabilities were frantically urged by physicians, relatives, friends and clergy to place their son or daughter in one of the State's facilities. . . "for the child's best interest and for your own." The family was only given the Hamlet-like choice. . .to institutionalize or not to institutionalize. In vivid contrast, in his 1984 State of the State address, Michigan's Governor James Blanchard set a goal for providing enough community based residential and support options so that no developmentally disabled child would have to live in a State institution or nursing home after the end of 1986.[1]

These nine illustrations of progress signal the fact that in Michigan and in the Southeast section in particular (a place seldom envied on the Sunset Strip or in the heart of Manhattan), developmentally disabled people are being treated in an enlightened way. They are regarded as citizens. They are living down the street

III. BEDROCK

When asked about the reason for this progress, I like to offer that values and not finances have made the difference. Other countries, states, even regions

---

[1]Governor James J. Blanchard, Michigan State of the State Message; Moving Ahead in 1984, January, 1984, p.42.

within this state, have the same or superior economic resources. Put another way, what is infinitely more necessary than money to a man born into a society that assigns his kind to an untouchable caste is for a fellow citizen to be so emotionally disquieted by the practice that he has to change it to regain peace of mind. What we have tried to do at Macomb-Oakland is to make the consciousness awakened in Scandinavia, Syracuse, Omaha and Brandeis free a man in Michigan.

Three values that we have braided into an ethic at M.O.R.C. have helped greatly in converting the recognition of injustice into a hard liberating practice. Staff are helped to acquire the following:

Sense of Urgency

I think it is commonly accepted that we Americans are an impatient people. We have been raised to believe that if indeed "time is not money" it at least is not something to be wasted. Being conscientious about our use of time is considered a key to success and certainly no one who languishes idly in our society is seen as someone likely to better himself. While Lewis Carroll's March Hare was an exaggeration more and more I think my friends and I are beginning to resemble the parody.

I hate to wait in lines at restaurants, gas stations, football games and, of course, being stalled in my driveway is one of the most maddening of all squanderings. I regard myself as a busy man who rather existentially is determined to embrace more than he can hold, to live a rich and full life. Monotony and boredom when forced on me -- at certain required events and obligations I regard as robbery.

Broderick reported in 1977 that the typical resident at Pennhurst had spent nearly two-thirds of his life in the institution and had benefitted from an average of 15 minutes of positive programming a day.[2]

A review of Macomb-Oakland group home residents four years ago revealed that the average adult client had received only six years of schooling in his or her lifetime.

I have a friend who spent over 39 years in a State Home and Training School. One of his hobbies remains to sentimentally travel the world through his Viewmaster slides. The institution kept him so tightly in a calendar warp that the leap from commercial still-shots to moving film is just beginning to attract his interest in this his 70th year.

After finishing a nice supper at a local Chinese restaurant in Detroit, a young social worker asked the two gentlemen he was dining with if they had enjoyed their meal. They heartily agreed it was delicious and both said they like eating in a restaurant. It was their first time. Charlie was 60 and Robert was 55.

How many other things have been denied? Racquetball, boat rides, parking, cruising drive-ins, garage sales, Bob Seeger Live, waterskiing,

---

[2]Broderick Opinion, December 23, 1977. U.S. District Court for the Eastern District of Pennsylvania, No. 74-1345.

using the bathroom in private, showering by yourself, bubble baths, midnight snacks, feeling like your life is going somewhere.

We who are enlightened as to the plight of the developmentally disabled must be impatient and adventurous on their behalf. We must protect against the waste of their time as jealously as we protect our own.

Sense of Ownership

It is popular today to blame others for the shape we find our human service systems in. Workers within the system and parents who depend upon it, have a limitless number of enemies, cads, or indifferent and faceless bureaucrats to blame for malfunctions or nonfunctions. How many times (and how many colorful ways) have we heard the real problem identified as: the Board, commissioners, civil service, money, news media, parents associations, local community or unique politics?

Projecting fault on others takes us off the hook.

The "projection" mentality can be comforting in a paradoxical way. It leaves us feeling powerless and out of the field of reponsibility. The powerless professional laments: "There is really nothing I can do." "I am sorry but my hands are tied." "I would like to help but it really isn't my job." "I know it isn't right but it is the policy."

The powerless parent excuses: "Oh, I know it isn't your fault." "What can one parent do?" "Well, after all, there are a lot of people who need help, too." "I suppose I should be happy with what I have."

While it might be fashionable to look for systemic solutions, analytically arrived at after problem studies, task force reports, procedure drafts, 90-day review, etc., nothing will ever replace the individual assumption of ownership for solving a client's problem -- or the problems of a group of clients. We cannot make an even trade of individual initiative for system accountability.

It is good to remember that the Interdisciplinary Team was never intended to supplant the conscience of its individual members. It was supposed to collect strength, wisdom and stimulate imagination. It was not intended to tease a pooled alibi from the group "professional." In this connection Charles Reich's Greening of America aptly cautioned us to be on guard for. . ."decisions made by experts, specialists, and professionals safely insulated from the feelings of people."[3]

We urge staff and parents to be the conscience of the agency, of the system, to recognize that the bureacracy can develop its own momentum without a direction. It must be guided. Client rights are not self executing. The truth will not set them free. Each of us owns the key to that door.

---

[3]Reich, Charles, Greening of America.

Commitment to Action

Many people have empathy for the developmentally disabled. If asked, probably every person passing a street corner would say that they "feel sorry," "hurt," "pity," or "wish the best for them." The situation is similar among parents and professionals. Each has a story to tell that grips their heart and the reason for their employment or volunteerism is because of that gripping for the individual who has the handicap, who is dependent entirely on family and staff, more is needed than hearts being touched. It is not enough for a parent to gain even the most profound insights as to why their handicapped child was put on this earth, not enough for a social worker to have developed even the most excellent working relationship with the school. These acquisitions are only significant if they propel us to alter the plight of the consumer.

Jane Addams, the tireless social activist in Chicago almost a century ago, put our obligations quite simply. . ."action is indeed the sole medium of expression for ethics."[4]

If we are caught up in this struggle of wanting what is best for people with mental retardation and similar conditions, then we have to convert our emotions into action. We have to act personally on behalf of consumers, not just when there is a huge group behind us. We have to act even if it means that a confrontation will result, even if that confrontation is with an enemy who is strong or a friend who is loved or a colleague who is influential.

We have to act even if it means getting dirty, being called radical, kook, unrealistic, unbearable, unprofessional. We have to avoid developing a style that for all its sophistication, leaves us like Daisey, The Great Gatsby's lover, in Fitzgerald's novel, who. . "Gleamed like silver, safe and proud above the hot struggles of the poor."[5]

The field is filled with good and talented people who no longer act. They have given up because the system wouldn't listen, didn't see the value in their ideas or their presence. This is indeed unfortunate because people with developmental disabilities cannot afford our brooding on the sidelines. It does the client absolutely no good for us to just feel deeply, to pout about a rejection, or to become cynically critical if we do not act to change the conditions that rob.

For all the complexities that are inherent to this case, the parent/professional responsibility is distilled to this: We have to personally decide not to permit someone we know to remain tethered to a life style we would find intolerable for ourselves.

It has been the experience on this part of the map that when even a few parents and professionals build their programs on bedrock values that reflect a sense of urgency, an acceptance of personal ownership for solving

---

[4]Addams, J., Democracy and Social Ethics, MacMillan Co., New York, 1913, p.273.

[5]Fitzgerald, F. Scott, The Great Gatsby, p.132.

problems, and compulsion to act on behalf of the consumer, progress cannot resist.

IV. PRACTICAL DIFFERENCES

Agencies and associations across the continent have discovered or created unique ways of battling successfully with their own service structures. I offer the following as a contribution to the war chest.

o Relationship with Parents

Cultivate this association like no other group. There can be great mutual satisfaction derived from treating parents as part of the solution and not a force to be endured. At Macomb-Oakland parents have their own association attached to community placements. They serve on Citizen Advisory, Human Rights, and procedure committees. Parents have an appointed Ombudsman and their own group home monitoring committee. At MORC, we have only placed one individual over the objection of a family. We have placed well over 1,100 with approval.

o Readiness Reversal

Long ago we discarded the notion that clients had to learn their way out of the institution. Rather than blaming the victim, we have put the burden on ourselves and said that virtually everyone can move into the community at large if we create the right alternatives, and if we prepare the people who will receive them and support them afterward.

o Elite Corps of Developers

Rather than leaving the creation of community placements up to citizens who take the initiative to come in off the street and volunteer their homes, or give the task to already burdened staff, we have assembled a corps of home developers. These staff have the exclusive responsibility for opening a set number of placements each year. They have become expert in building codes, interest rates, balloon payments, zoning law and more. These are specialties which are essential to providing housing to our clients but seldom addressed in graduate school.

o Embracing the News Media

Thanks to a unique point of view brought to us by our public information director, at Macomb-Oakland we no longer sit back and hope the news media finds a conscience and does a sweet story. We have gone after coverage, established good relationships with reporters and editors. Through frequent contact we have kept the responsible news media personalities informed on significant issues and familiar with the focus of the struggle. Well balanced reporting and strong editorial support have been the dividends of this approach.

o Products of Social Change

Most of us who are part of this human service industry were unfamiliar with the reactions elicited by programs the normalization principle fostered. Having elected officials upset, homeowners litigating, news stories breaking about neighborhood resistance, ARC's divided into bitter camps, Department Directors on the defensive or on the muscle are new to us. Recognizing that these outcomes are a predictable part of social change, that they accompany most/all social reform, and are not indices of our thrust being wrong removes the chill from reaction. We need to retain a clear sense of perspective if community based options are to be delivered. A perspective of social history, what to expect and why, is necessary when tradition is challenged. Old ways die hard.

o Reading and Heroes

For years I struggled with the professional journals, trying to become a student of the profession. Perhaps it was above me or beyond but I seldom found anything on the pages of our "literature" that helped me or helped the people I was responsible for. I have gone back to the reading habits that lead me to this field and rediscovered the heroes that deserve the awe. Jane Addams, Saul Alinsky, Mohandas Gandhi, Paul Gauguin, Martin Luther King, Rosa Parks, Albert Schweitzer. New reading that has been compelling: Human Options by Norman Cousins, You Can Negotiate Anything by Herb Cohen, The Hunchback of Notre Dame by Victor Hugo, A Mind that Found Itself by Clifford Beers, Joey by Joseph John Deacon, Joys and Sorrows by Pablo Casals.

o Avoid Seductive Traps

There are a great many distractions that can lead us off the mark in this work, two that are especially effective follow. Steer clear at all costs.

Purism Trap This pitfall is well illustrated by those who criticize the small group home as being ideologically impure yet feel no compulsion to work at breakneck speed to introduce six institutionalized people to the community in a more "acceptable" manner. Here the purist is enamored more by adherence to a relative personal principle than to a consumer's absolute condition.

Trap of Grand Design While it would seem to make perfect sense to devise comprehensive plans for our service systems, the consumer can find little value in them if they take so long in the creation that all opportunity has wrinkled in the process. Planning should not come at the expense of the handicapped consumer. Life cannot be put on hold while a five-year plan is drawn.

o Man-Woman Power

Include in your organization a good sprinkling of people with TYPE A personalities. (Avoid exclusivity, too many will make your agency or association

spiral through the clouds.) Recruit coffee chuggers, Rolaid grinders, chain smokers, and those with deeply knot brows.

o Parent Monitoring

We have worked with the Parents Association to establish a committee that monitors each of our group homes on a bi-monthly basis. The criteria used is a mixture of borrowed standards, principles and homespun values. The committee evalutes the home's "atmosphere" and "feel" to see if it squares with what the agency has promised. Rather than the monitors being seen as intrusive, they have been welcomed by providers and have been responsible for hundreds of environmental improvements. Parents who are considering the move from institution to group home also are comforted by the fact that parents have a formal role to play in the program's operation.

V. THREATS TO MOMENTUM

While we have made wonderful progress in this field, there are of course certain phenomena that threaten our gains. Five of the more significant challengers to our momentum follow.

1. Prejudice Opposition to community placement (mainly group homes) is becoming more sophisticated, more finely tuned. "Overconcentration" arguments have replaced "property values" but it is still the same prejudice that has kept developmentally disabled in caricature communities for 100 years.

2. Complacency Community placement is threatened whenever professionals and parents become self-satisfied with their own accomplishments and say, "I have done my share. Let someone else do something for a change."

3. Groomed Fatigue When we spend more time reinforcing one another for being tired, overworked and burned out than giving encouragement and awards for working hard, for working imaginatively, and working with daring, community placement is threatened.

4. Elitism Community placement is threatened when parents and professionals create their own stigmatizing heirarchy within which to place developmentally disabled people, and then use the stigma to exclude. When consumers who have lived within institutions are disparaged, and calls for their segregation are made by parents who have kept their sons and daughters at home, community placement is threatened.

5. Pull of Institutional Gravity Even though institutions are shrinking, the regimentation and depersonalizing practices that haunt them also haunt community placement. Impersonal labels (for example: "facility," "males," "females," "non-ambs," "Hepatitis B carrier") are slipping into everyday language. When homes become more attentive to schedules, job assignments, efficiency, order, staff convenience and resident control than to teaching, nurturing, and creating a warm atmosphere,

we have succumbed to the pull of institutional gravity and it eats at the very soul of community placement just as it did to programs born in terrazzo dayrooms.

Each of these, and their combination which sometimes surface in a kind of innocently inspired parent-professional collusion, is a manageable threat. They still must be watched, re-examined and rooted out whenever possible. There is not, however, a single challenge with the exception of our indolence that can stop the march people with developmental disabilities are making today.

VI. KEEPING THE RUDDER STRAIGHT

During the activist period of the late sixties and early seventies, one of the caveats was to be wary of being "co-opted". We used to suspiciously avoid even looking like we were part of the system, to say nothing of the lengths we would go to resist its influence. I think sometimes today our clients would be better off if we who work on their behalf would be less tolerant of the interagency and social structures that have trapped so many handicapped people on the margin. In our genuine attempts to work within the system, we can easily get caught up lunging from one expedient to another until our sense of direction (if not our sense of urgency) is blurred.

In an interview a few years ago, Adlai Stevenson III was lamenting President Carter's having gotten himself so tangled up in detail that he lost sight of his objectives. Stevenson reflected. . ."The great Presidents of the country have been men who had little time nor preoccupation with management nor the problems of administrative routine. Instead, they have been men who had an agenda for the country."

I think as we find ourselves buried in the routine of paper, calls to return and emergencies to solve, we must keep a tight grip on the agenda.

I would suggest that our part of this agenda, for people with develpmental disabilities is to help them live among us and lead lives that are rich and full. We as parents and professionals must help them attain, not accreditation but participation, not acceptance but prosperity, not normalization but self-actualizaton, not community palcement but citizenship. The stakes are immense.